# Promising Practices in Long Term Care Systems Reform: Wisconsin Family Care

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# WISCONSIN FAMILY CARE

As home and community-based support systems continue to grow and evolve, states are examining whether their current systems reflect fundamental participant and community values. A number of states are concluding that they need to put in place systemic reforms to ensure that their home and community-based support systems promote dignity, independence, individual responsibility, choice, and self-direction.

Systemic reforms are simultaneously addressing multiple aspects of community long term support systems in order to improve responsiveness to participants' needs and preferences. These initiatives are developing entirely new ways of designing, organizing, and managing community-based supports as a system rather than as a random collection of uncoordinated individual services. In some cases, this has required states to make fundamental changes to the administrative infrastructure of their home and community- based support programs.

Two design features in particular have repeatedly emerged as essential components of systemic reform initiatives:

- *Single Entry Points*, which provide persons with a clearly identifiable place to get information, advice and access to a wide variety of community supports; and
- *Person-Centered Services*, which place participants, not services or providers, as the central focus of funding and service planning.

The Centers for Medicare and Medicaid Services contracted with Medstat to examine approaches ten states took to developing Single Entry Points and Person-Centered Services to assist persons with disabilities to live productive and full lives in integrated community settings. We conducted on-site interviews with state officials, advocacy organizations and local program administrators and extensively reviewed written documents on policy proposals, administrative rules, and program evaluations. The emphasis of the resulting ten case study reports is on identifying transferable models that can be adapted for replication in other states and communities across the country, while acknowledging that some aspects of state systems may be unique to each state's culture, history and traditions.

## *Overview of Wisconsin Family Care*

Wisconsin has long been a national leader in establishing creative long term support systems that flexibly respond to the preferences and needs of program participants. Building upon its extensive experience and capacity, Wisconsin has launched a new initiative called Family Care that redesigns its long term supports system by concurrently reducing its complexity and increasing participant choice. One of its most groundbreaking features is the way it concretely translates into policy the principle of "money following the person" by creating for program participants an entitlement to both community supports and institutional care.

Developed with the extensive involvement of persons with physical disabilities, developmental disabilities, older persons and their representatives, Family Care seeks to achieve four specific goals:

- *Give people better choices about where they live and what kinds of services and supports they get to meet their needs;*
- *Improve access to services;*
- *Improve quality through a focus on health and social outcomes; and*
- *Create a cost-effective system for the future.*

From the start, these goals served as the guiding principles for making detailed decisions about Family Care's design. By embarking on a strategic planning process that anticipated and mapped out every conceivable issue, Wisconsin's Department of Health and Family Services was able to consistently apply these goals to the development of specific policies, operational procedures, management tools and quality performance measures. Thus in a comprehensive manner, Family Care's goals and values are reinforced in vehicles ranging from program descriptions directed toward the general public to reporting requirements aimed at care management organizations.

Locally, Family Care's goals are carried out through two county governmental organizations:

- Aging and Disability Resource Centers provide a clearly identifiable single entry point for information, advice and access to a wide range of community resources for older people and persons with disabilities. For persons seeking assistance with long term supports, Resource Centers assist them to make informed choices about their options. They also provide functional and financial screening to determine eligibility for publicly financed services and to enroll them in Family Care.

- Care Management Organizations (CMO), manage the Family Care benefit, which provides enrollees with choices about the types of long term supports they receive and the setting in which they are provided, ranging from one's own home, community residences and institutions. By consolidating funding from multiple program authorities into a single capitation payment to the CMO, Family Care seeks to organize services around individual needs and preferences, rather than around allowable services and designated providers.

To enable program participants to access a flexible set of choices through a streamlined delivery system, the Centers for Medicare and Medicaid Services awarded Wisconsin several Medicaid waivers:

- Section 1915(c) waivers permit the state to provide home and community-based services (HCBS) to older persons and persons with physical and developmental disabilities who qualify for institutional care, and
- A Section 1915(b) waiver permits the state to make Medicaid HCBS in five pilot Family Care counties available only to persons who choose to enroll in a CMO.

Prepaid Health Plan contracts are the vehicle used by the Department of Health and Family Services to make capitation payments to the CMOs that combine funding for home and community-based waiver services, state general revenue funded programs and long term care related Medicaid state plan services such as home health, therapies, personal care, durable medical equipment and nursing home care. CMOs are not responsible for providing primary and acute health care services. They are, however, expected to help enrollees coordinate their health care and support Family Care members in achieving "the best possible health."

Currently the full Family Care pilot is operating in five counties that encompass seventeen percent of the state's eligible population. In four of the five counties, the program serves all three of its target populations—persons with physical disabilities, persons with developmental disabilities and older persons. Milwaukee County, where over half of the state's Family Care participants reside, has limited its pilot to enrollment of older persons. As of February 1, 2003, a total of 6,840 persons in these five counties were enrolled in Family Care.

Four additional counties operate Aging and Disability Resource Centers without having a Care Management Organization that provides the Family Care long term support benefit. As providers of comprehensive information about community supports for older persons and persons with disabilities, they offer the same services as the Resource Centers in the other counties except for Family Care eligibility determination and enrollment.

To provide a complete picture of the goals, design and operation of the Family Care Program, this report will highlight the community supports programs from which it evolved, the redesign process that created it, the importance of achieving consensus on values that would guide systems redesign, and the critical role played by stakeholders in defining Family Care's guiding principles and translating them into operational policies. Each of these factors made unique contributions to the program's ultimate structure. In addition, an in depth description of Family Care's essential components and their role in achieving the program's goals will be provided, along with lessons other states can gain from Wisconsin's experiences.

## *Evolution of Wisconsin's Community Supports Programs*

Wisconsin has long been recognized as a national leader in developing flexible and creative community supports for older persons and persons with disabilities. Its current array of innovative home and community-based supports is a testament to its willingness over the past two decades to experiment with new approaches.

Its first systemic long term care reform initiative dates back to 1981 when, in an effort somewhat similar to the recent one that created Family Care, Wisconsin established the Community Options Program. Considered groundbreaking at the time, the Community Options Program (COP) financed supports chosen by participants through an individual service planning process. Instead of specifying a concrete set of allowable services, the state permitted COP funds to be spent for any support preferred by participants that would help them continue living in the community. All populations needing long term supports were covered including older persons, persons with physical disabilities or developmental disabilities, and persons with mental health needs. County governments were designated to administer the program locally, consistent with

their traditional role in managing most of the state's health and human services programs. To limit the growth of public spending on institutional care, a moratorium on construction of new nursing home beds was also enacted. That moratorium remains in place today.

Strong partnerships were established between the advocacy organizations and the management team of state officials that designed COP and pushed for its passage. An integral component of the design strategy was the development of broad consensus on the principles and values upon which the program would be based. Thus, the groundwork was laid in 1981 for efforts undertaken over the next two decades that would expand Wisconsin's system of community supports, while maintaining its underlying values.

These program expansions were achieved in large measure by securing Medicaid home and community-based services (HCBS) waivers. Wisconsin was initially reluctant to fund COP through a waiver due to concerns that Medicaid rules would limit the program's flexibility. However in the mid-1980's, when COP had become fully implemented statewide, Wisconsin obtained two waivers targeted to older persons and persons with physical disabilities and two waivers serving persons with developmental disabilities. In addition to the waiver programs, it continued COP as a discrete state general revenue funded program to finance supports not permitted by federal rules and to cover persons who do not meet Medicaid waiver eligibility standards. More recently Wisconsin established a waiver program for persons with brain injuries. Almost 26,000 persons received supports through these programs in 2000.

During the 1990's, Wisconsin continued to adopt both state specific innovations and national demonstration programs, including the Community Supported Living Arrangements demonstration and the Self Determination Project targeted to persons with developmental disabilities. The state funded Alzheimer's Family and Caregiver Support Program, providing up to $4000 in supports to families caring for a relative with Alzheimer's disease, became a model for the design of the National Family Caregiver Support Program.

In 1994 the state began developing the Wisconsin Partnership Program, targeted to older persons and persons with physical disabilities who meet nursing home level of care criteria. It integrates financing and delivery of acute, primary and long term care services through capitation payments to each of four community based service organizations across the state. Drawing upon features of the national PACE program, the Partnership Program adopted several policies designed to increase participant choice, such as contracting with primary care physicians chosen by each enrollee, permitting participants to select and direct the work of their personal care workers, and enabling persons to receive supports primarily in their homes rather than through adult day care centers. In October of 2002, 1352 persons were enrolled in the Wisconsin Partnership Program.

**Impetus for Reform**

In the mid-1990's the state managers who over the past fifteen years had designed Wisconsin's community supports innovations, together with the increasingly sophisticated advocacy organizations representing Wisconsin's aging and disability communities, decided that major systemic changes were needed in the organization and financing of the state's long term supports

programs. They concluded that while each program had many successful features, taken as a whole, they formed a system that was complex, fragmented and expensive.

Three factors provided the major impetus for reform:

***Access to community supports***--It had become increasing difficult for persons to get assistance from Wisconsin's primary community supports programs—the Medicaid HCBS waiver programs and state funded COP. Their features of flexibility and choice that made them so popular contributed to long wait lists that in some counties resulted in delays of several years before individuals could receive services. For older persons and adults with physical disabilities, nursing home admission became the default option. Likewise, persons with developmental disabilities were unable to transition to the community from ICF/MR facilities because waiver slots were unavailable. Thus, the principles of having an even playing field for entitlement to both community supports and institutional care and of enabling public funding to follow the person to desired living settings became a driving force for reform.

***Complex and fragmented delivery systems***--The downside of the state's creative use of new program authorities meant that the community supports system had become complex and fragmented. Figuring out how to obtain services was difficult for both persons who qualified for publicly funded supports and for those who could pay privately. From a management perspective, the more costly state plan services were not well coordinated with the major community supports programs administered by the counties. Separate entities authorized institutional care and community supports. Likewise, state plan personal care services were not well coordinated with waiver services. With waiver services authorized by county-based case managers and personal care services authorized by a state level paper review, these two programs could often be duplicative. Over one third of personal care expenditures were attributable to waiver programs participants. Thus, one outcome sought by the reform effort was to be able to manage the entire long term care system rather than just its discrete parts.

***Costs***--The overall cost of Wisconsin's long term care system was a major impetus for reform. Data presented during the redesign effort illustrated that in comparison to other states, Wisconsin's overall spending was relatively high. The balance of spending between institutional care and community supports was also a concern. In 1997, following fifteen years of concerted efforts to achieve a more cost effective system, two-thirds of total long term care expenditures for all populations was being spent on institutional care. Also seen as contributing to high overall systems costs was the lack of coordination between the management of waiver services and related Medicaid state plan services. Making the entire long term care system more cost effective was seen as a way to free up resources to eliminate wait lists and provide an entitlement to community supports for all who qualify.

**Long Term Care Systems Redesign**

An ad-hoc coalition of state-wide advocacy organizations representing older persons and persons with developmental and physical disabilities issued a paper in 1995 calling for major long term care systems reform. Concurrently, seeds of reform were growing within state government; yet policy disagreements between the Division of Supportive Living which manages the state's

community-based services programs and the Division of Health Care Financing which manages the Medicaid program thwarted significant progress on systems redesign within what is now the Department of Health and Family Services. Thus in 1996, the time was ripe for creation of the Center for Delivery Systems Development in the Office of Strategic Finance. Since the Office of Strategic Finance is the Secretary's arm for developing and managing the Department's budget, it was in a strong position to achieve consensus across Departmental divisions.

The Center for Delivery Systems Development's new director, Thomas Hamilton, and many of its staff transitioned from the Bureau of Long Term Support, which provided the management leadership for implementation of COP and the HCBS waiver programs. Additional positions were created to recruit staff with specialized technical skills, such as rate setting, that the Center was lacking.

Thus began a two-year effort to redesign the state's long term care system. Three steering committees of stakeholders were established to advise the department about aging and chronic conditions, developmental disabilities and physical disabilities. In addition a series of focus groups and public forums were held across the state with older person and persons with disabilities. One advocate has compared the number of people participating in committees and workgroups to the cast of *Ben Hur*.

The systems redesign effort hit one major bump along the way. In 1997 the Secretary of the Department of Health and Family Services released a long term care reform plan that differed in several important ways from the provisions developed collaboratively with the key stakeholder groups. In particular, the Secretary's plan called for a managed care approach that would integrate a comprehensive set of acute, primary and long term care services rather than limit integration to the state's various community and institutional long term care funding streams.

Advocates were adamantly opposed to the plan. They were concerned that if service integration were to extend beyond capitation payments for long term care, the state's flexible community supports system developed under COP would be destroyed. Since most spending in a fully integrated system would have been for acute and primary health services, medically oriented HMOs, inexperienced in providing person driven supports, were viewed to be the most likely contractors. Although the state had some previous success in developing several small, integrated health and long term care Partnership Programs using community-based lead agencies, the Secretary's proposal covered acute, primary and long term care services for thousands of enrollees. Such a plan, it was assumed, could only be administered by large managed care organizations.

The Department's plan was quickly withdrawn after several contentious public hearings. Following fence mending efforts with the advocacy community, the Secretary created the Redesign Consolidated Steering Committee to assist in resolving remaining disagreements between stakeholders and state officials. In his 1998 State of the State message, Governor Tommy Thompson proposed the creation of Family Care and directed the Department to further flesh out the program's design. Later that year the Department released a consensus proposal that resolved the earlier disagreements, and with stakeholder support and advocacy, the plan was enacted into law in 1999.

**Role of Values in Guiding System Redesign**

Establishing consensus on the values that would guide systems redesign was considered by state officials to be an essential first step. Such an effort had laid the groundwork for the initial design of COP and for the incremental changes made to the state's community supports system over the years. From that previous experience state officials learned that establishing systems values that are broadly held by diverse interests such as state and county officials, advocates, providers, and program participants can serve several useful functions.

***First***, and most obviously, a values based framework can guide program and policy decisions. When disagreements arise over program details, values can serve as a yardstick to measure the extent to which various approaches achieve the end goals. In Wisconsin, values such as having program money follow the person and creating a level playing field between community supports and institutional care led to the policy decision of making home and community-based services an entitlement that has equal standing with institutional care.

***Second,*** articulating the goals and values a program seeks to achieve rather than its structure and administrative mechanics helps policy makers and the general public understand the benefits it would provide their own families.

***Third***, clearly stated goals that are reinforced at every opportunity guide both staff and advocates as they implement the program. Given the complexity of efforts like Family Care, developing written policies governing every conceivable situation is not feasible. Using goals as a continual reference point helps keep decision making at all levels consistent with the values framework.

***Fourth,*** in Wisconsin its values framework served as the basis for a wide range of program tools and resources. For example, the explicit goal of the Resource Allocation Decision Method is to instill participant values and outcomes into the daily practices of Family Care case managers. Likewise, measurement of CMO performance outcomes focuses to a large extent on how well participant goals are being met. Tools that empower participants to make informed decisions include publications like "Being a Full Partner in Family Care" that describe in a detailed yet straightforward manner what an enrollee can expect from a CMO and where to turn if their expectations are not met.

**Stakeholders Roles in Program Implementation**

One of the values firmly held by Wisconsin state officials is to continuously incorporate the participant's voice into all aspects of policy development and implementation. Often states articulate this value, but fall short in making it a reality. In Wisconsin it is concretely translated into the governing and oversight structures of its programs.

As previously noted, stakeholders were real partners with the state in designing Family Care. Through four types of structures, advocates and program participants provide ongoing direction to program implementation.

At the state level, the Wisconsin Council on Long Term Care was created by the Family Care statute and was given four specific responsibilities:

- Advising the state on general long term care policy development;
- Guiding implementation of the Family Care pilots;
- Monitoring and reviewing patterns of complaints, grievances and appeals; and
- Reporting annually to the Governor and the legislature about significant achievements and problems related to Family Care implementation.

When it was scheduled to sunset two years later, the Secretary of the Department of Health and Family Services reconstituted it as an advisory body to the Department with similar and more specific responsibilities.

Over one-half of the Council's members are program participants or their representatives. Evidence of its significant role in shaping long term care policy can be found in the minutes of its monthly meetings, published on its own web site www.wcltc.state.wi.us. The Council has taken on difficult tasks like serving as a mediator with key stakeholders such as providers, county pilots and the Department in resolving disagreements over Family Care administrative rules, and being an independent voice when the Governor's budget eliminated funds for advocacy and planned Family Care expansions. It is also a vehicle for broader stakeholder input, particularly as a conduit for input from and support to the local long term care councils.

Local long term care council membership is also composed of over one-half program participants or their representatives. Their charge is to establish the initial plan for the structure of their county's Resource Center and Care Management Organization and on a continuing basis, advise the CMO on the adequacy of its provider networks, identify service gaps, monitor participant complaints, and track patterns of CMO enrollments and disenrollments. Its role is advisory, in contrast to the roles of the Resource Center and CMO governing boards described below. The State Long Term Care Council has been concerned that local councils are not adequately prepared to carry out their functions and is working with the Department to develop training manuals to convey the knowledge and skills needed by local councils to effectively oversee Family Care.

The other two bodies with stakeholder membership are the governing boards of the county Resource Centers and CMOs. At least one-fourth of their members must be program participants or representatives and their total composition must be reflective of the ethnic and economic diversity of the area served. Since these bodies have decision making responsibilities, their roles are clearer cut than those of the local long term care councils.

Separate boards, without overlapping membership, are required by state statute and federal rules in order to achieve a structural separation between these two county governmental organizations. A conflict of interest can occur in a managed care system when assessments of participant disability levels are performed by the same organization that receives capitation payments based upon the functional status of their enrollees. As a result, two distinct entities are required. Besides having responsibility for general governance matters, the CMO board is statutorily

required to assure the CMO's separation from eligibility determination and enrollment counseling functions.

## *Single Entry Points: Aging and Disability Resource Centers*

One of Family Care's goals is to improve access to services. Aging and Disability Resource Centers provide a clearly identifiable place organization where the public can obtain information on a wide array of community services available to older persons and persons with disabilities. Although they were established as part of the state's long term care reform initiative, the scope of information and assistance they are expected to address includes such varied areas as transportation, employment, food stamps, home maintenance, and legal problems. Their prevention and early intervention mission is reflected by community education activities that focus on reducing the risk of disabilities, such as fall prevention and physical fitness programs.

The breadth of their role is in part intended to establish them as a credible community resource so that when individuals need more in-depth assistance with long term supports, the Resource Centers will be a trusted entry point. Their contracts with the state require them to conduct outreach and marketing activities to promote public knowledge of their role as service entry points. Recent data indicates that about one-half of the inquiries made to the Resource Centers are related to health and long term care issues while the other half address more general needs of older persons and persons with disabilities.

In addition to this broad information clearinghouse function, the Resource Centers provide intensive assistance on specific matters. Elderly and Disability Benefits Counselors help people with problems they may be having with Medicare, Social Security and other public benefits. Crisis intervention and emergency services are available on a 24-hour basis as are elder abuse and adult protective services.

Older persons and persons with a disability who contact the Resource Centers in search of specific advice about long term supports are offered Long Term Care Options Counseling, which provides individually tailored information about available services. Such counseling may lead to an in-home visit by Resource Center staff to administer the Long Term Care Functional Screen so individuals exploring their supports needs can have concrete personal data upon which to make informed decisions. Like all of the Resource Centers' services, these counseling and screening services are provided to persons without charge, regardless of whether they are seeking eligibility for publicly financed benefits.

**Pre-Admission Counseling**

To ensure that persons considering admission to long term care facilities are aware of the full range of available options, nursing homes, residential care facilities, and adult family homes must inform all potential residents of the Resource Center's services, the Family Care benefit, and the availability of functional and financial eligibility screens. For persons whose long term supports needs are expected to last more than 90 days, facilities are required to refer them to the Resource Center for a pre-admission consultation.

Unless an individual declines to participate, Resource Centers are required to provide the potential resident with pre-admission consultation consisting of long term care options counseling, and functional and financial screens. Consistent with Family Care's philosophy of arming persons of all incomes with information to make their own choices, persons who pay privately for their services as well as those eligible for public benefits are referred for pre-admission consultations.

Facilities have responded in differing ways to this new requirement, enacted as part of the Family Care statute. Hospitals were originally included among the providers required to refer to Resource Centers persons seeking admission to long term care facilities. Because fines of up to $500 could be imposed for each violation, hospitals began making pre-admission consultation referrals for all older persons and persons with disabilities seeking discharge to long term care facilities, not just those who were likely to require long term supports for more than 90 days. As a result, Resource Centers were overwhelmed with inappropriate referrals of persons needing only short-term rehabilitation. The state has suspended this requirement for hospitals and has issued guidelines encouraging voluntary referrals.

In contrast, long term care facilities such as nursing homes, residential care facilities and adult foster homes that actually admit residents with long term care needs were not making pre-admission counseling referrals on a consistent basis. To achieve greater compliance, the state began an aggressive enforcement effort. A state policy memo sent to long term care facilities informed them that as part of the annual survey process, a random sampling would be made of new admissions to determine whether pre-admission counseling referrals had been made. If they were not made, fines would be imposed. Since December of 2001 when the directive was issued, referrals to Resource Centers for long term care options counseling and functional and financial screening have doubled.

**Access to the Family Care Benefit**

Besides providing information and advice about long term supports options, the Aging and Disability Resource Centers are the single entry point for individuals to gain access to the Family Care benefit. The same Long Term Care Functional Screen provided to persons as part of pre-admission counseling is used to assess functional eligibility for Family Care. Since Family Care covers a broad range of services, integrates multiple funding streams, and serves several populations, the state's challenge was to develop an instrument that would be valid for measuring many aspects of individuals' situations, regardless of their current living arrangement.

Two parts of the instrument's name may, in comparison to terms used in other states, give a misleading impression of its scope. Wisconsin's "Screen" is a very comprehensive tool that documents information about a person's demographic characteristics, living arrangements, ADL and IADL functioning, medical diagnoses, health related needs, cognition, behavior and risk factors. Depending upon an individual's circumstance, it can take as long as a couple of hours to administer. For eligibility purposes, it primarily measures "Functional" need, but with Family Care's emphasis on promoting both social and health outcomes of its members, the screen collects a substantial amount of information about an individual's health condition.

Resource Center staff who administer the Long Term Care Functional Screen must have a bachelor's degree in health, social services or a related field, and complete an interactive web based training course developed by the University of Wisconsin-Madison under contract with the Department of Health and Family Services. The training presents a series of case scenarios that permit staff to conduct trial screens. Only after passing an on-line certification exam can staff gain electronic access to the Functional Screen.

***Functional eligibility criteria***--The Long Term Care Functional Screen calculates an individual's level of care and functional eligibility for Family Care. Persons determined to be eligible for institutional care qualify for Family Care at the comprehensive level of care. Persons who quality for Family Care at the intermediate level are not eligible for nursing home care, need help with fewer daily activities and are either financially eligible for Medicaid or in need of adult protective services. Less than two percent of current Family Care enrollees have an intermediate level of care. As implementation of Family Care is phased in, an increasing proportion of a CMO's capitation payment is based upon the functional status of its enrollees. Therefore, not only is the distinction between a comprehensive and intermediate level of care important, but within each level, gradations of participants' functional status affect aggregate capitation payments.

Since the Long Term Care Functional Screen is a web-based application, County Economic Support Units, which are responsible for determining an applicant's financial eligibility, can access the screen's results to verify functional eligibility. More importantly, the electronic file of a person's Functional Screen is provided to the CMO case management team once an individual's enrollment in Family Care has been completed. This information then becomes the starting point for the participant's assessment conducted with the CMO, leading to the individual service plan.

***Financial eligibility criteria***--An individual can qualify financially for Family Care enrollment in two ways. One is to meet the state's financial eligibility requirements for Medicaid HCBS waiver programs. Wisconsin's waiver criteria uses most of the available federal options to maximize the number of persons who financially qualify, including an income standard of 300 percent of SSI, medically needy provisions, and spousal protections up to the federal limit.

The other way to financially qualify for the Family Care benefit is by having service plan costs that exceed one's gross monthly income plus one-twelfth of countable assets. By design, non-Medicaid standards permit persons with higher assets and incomes to become eligible for Family Care. County Economic Support Units calculate cost sharing amounts for persons in both eligibility groups based upon a combination of their service plan costs and financial resources. Only four percent of current Family Care members are ineligible for Medicaid.

As pilot counties began phasing in Family Care, they first enrolled current participants in COP and in Medicaid HCBS programs. Priority was given to these persons since upon federal approval of the state's 1915 (b) waiver request, services provided under HCBS waivers and state funded programs are only available to individuals who choose to enroll in Family Care. Next counties enrolled persons on service wait lists and then opened enrollment to new members who had not previously sought supports from county administered programs. Some enrollees in this

latter group were adults with physical disabilities who were receiving personal care and home health services under the Medicaid state plan and as a result had no contact with county programs since their services were authorized at the state level.

**Enrollment Consultation**

When the Centers for Medicare and Medicaid Services permitted Wisconsin to use county governments to both determine an applicant's level of care and administer a delivery system financed through risk-based capitation payments, it required the state to take several steps to address potential conflicts of interest. One of those steps, as previously noted, was to assign key program functions to two separate agencies in county government. A second step was to have enrollment consultation performed by an organization that is not associated with county government in order to ensure that potential Family Care members with costly support needs are not discouraged from program enrollment.

The Department of Health and Family Services has contracted with the Southwest Area Agency on Aging to provide enrollment consultation. Resource Centers in the five full pilot counties notify an enrollment consultant when an applicant's financial and functional eligibility has been established. The consultant reviews with the applicant key features of Family Care so they understand the implications of participating in a managed care program and provides information about other options. In four of the five counties a person's options are to join Family Care or be limited to receiving Medicaid state plan services such as personal care on a fee for service basis; services funded by COP and the HCBS waiver programs are now only available through Family Care. Persons in Milwaukee County also have the option of enrolling in PACE or in Wisconsin Partnership, the state's other two managed long term care programs.

Stakeholders have commented that enrollment consultation simply adds an extra layer to program access since applicants would not go through the intensive Long Term Care Functional Screen and income eligibility determination process if they did not intend to enroll in Family Care. Members of the state Long Term Care Council have suggested that a separate enrollment consultation process can undermine the mission of the Aging and Disability Resource Centers to provide streamlined access to services. In response to this concern, Department has required the resource centers to develop an "access plan" to address transitions between the eligibility determination process and enrollment consultation.

**Family Care Entitlement**

The Family Care statute establishes an individual entitlement to Family Care benefits 24 months after a CMO first accepts a capitated payment. Entitlement to benefits has been achieved for persons at the comprehensive level of care and for persons at the intermediate level who are either financially eligible for Medicaid or are former participants in state funded supports programs that preceded Family Care. Entitlement has not been achieved as authorized in the statute for non-Medicaid eligible persons who either have a comprehensive level of care or have an intermediate level of care and need adult protective services. Until July 2002, enrollment of these groups had been frozen due to budget restrictions.

At the beginning of fiscal year 2003, state funds were made available to permit two groups to enroll in Family Care. The state's policy memo to Family Care pilots emphasizes however, that enrollment could be frozen later in the year if state funds are insufficient, so continued program access for these individuals is not yet guaranteed. Stakeholders have been concerned that the freeze on enrollment of persons who are functionally eligible for nursing home care but financially ineligible for Medicaid was undermining an important principle of the long term care systems redesign—that there be no cliff for income eligibility by permitting persons ineligible for Medicaid to pay for a portion of their service costs on a sliding fee basis.

## *Person-Centered Services*

This series of case studies on state long term supports initiatives focuses on two primary components of systemic reforms. The first, as described in the previous section of this report, is single entry points, designed to be an identifiable organization where people can get information, objective advice and access to a wide range of community supports. The other essential component is a system of person-centered services that places participants, not services or providers, at the center of funding and service planning.

Person-centered services systems, as presented in the following sections of this report, have three key features. First by financing a wide range of support options, they enable persons to make meaningful choices about their living arrangements, types of supports they receive, and the manner in which services are provided. Second, by designing person-centered quality management and payment systems, the state's ability to achieve intended participant outcomes and program goals is enhanced. Third, by coordinating person-centered services with community resources, residents of institutions have access to enhanced assistance in transitioning to community living.

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**Person-Centered Support Options: Role of Care Management Organizations**

Persons eligible for Family Care bring to Care Management Organizations a capitation payment that finances supports provided in community, residential, and institutional settings. The Family Care benefit includes supports previously funded by the Community Options Program and several HCBS waivers--all of which had an extremely broad and flexible array of covered services--as well as the Medicaid state plan services of home health, therapies, personal care, durable medical equipment and institutional care. By making CMOs financially at risk for meeting the long term support needs of their members, the state expects that cost incentives will lead them to support enrollees in their own homes as the preferred and most cost effective setting, rather than in institutions.

**Individual Service Plans**—Each Family Care participant has an interdisciplinary case management team that, together with the enrollee, conducts a comprehensive in-person assessment of the member's needs, preferences and values. Starting with information collected by the Long Term Care Functional Screen, the social worker/nurse team uses a process called the Resource Allocation Decision Method to lead the participant and the team through a decision tree about outcomes the member desires and the supports and services that will achieve those outcomes in a cost effective manner.

Family Care has established 14 member outcomes grouped into three areas: self- determination and choice, community integration, and health and safety. (For a description of Family Care outcomes, see page 15) For each of these, participants define their own specific personal outcomes that form the basis for selection of supports to be included in their individual service plans. Since the state's quality assurance process measures whether each enrollee's personal outcomes are being met, care managers have a big incentive to align supports planning and service authorization with outcomes desired by the participant.

**Self-Direction—**As illustrated by the assessment and service planning process, participants provide self-direction on a number of levels. Service planning is driven by participant choices, desired outcomes, and selection of program-funded supports to achieve those outcomes. In certain circumstances, participants have the right to choose and supervise their own workers. For services that involve meeting intimate personal needs or having a provider frequently come in to one's home, the CMO is required to purchase services from any qualified provider requested by the enrollee, including a family member other than a spouse. The level of direction an enrollee can assume includes choosing, training, and supervising the worker and negotiating the work schedule. Under this option the employer of record is either the CMO itself or a subcontractor, not the enrollee.

The highest degree of participant control is through the self-directed supports option, which enables persons to manage the cash value of their entire Family Care benefit. Each CMO has developed its own procedures for implementing this option, but at a minimum, they must inform all participants of its availability, assist members to arrange for and manage the supports purchased, track enrollees' spending under their individual budgets, and monitor members' health and safety.

Persons choosing the self-directed supports option work with a case management team to assess support needs and desired outcomes in the same manner as all other enrollees. The CMO then establishes an individual budget based upon an amount it would have spent if it were providing services itself. Members can develop service plans to self-direct all or some of their services and can purchase supports that are not part of the CMO's defined benefit package as long as the supports help achieve personal outcomes. Self-directed service plans must be approved by case management teams, but the CMO needs solid justification for any denials. Fiscal intermediaries handle provider payments and related functions on behalf of the enrollee, including being the employer of record.

Since CMO's had until January 2003 to make the self-directed supports option fully available to its members, it is too early to tell how many persons will use it. However, enrollees have frequently selected and supervised their own providers in the Family Care program and in the state's HCBS programs that preceded it.

**Health Care Coordination—**Recognizing that persons in need of long term supports often have multiple chronic health conditions, Family Care has incorporated specific methods for coordinating attention to enrollees' health and long term supports needs. State officials noted that having nurses as members of interdisciplinary care management teams produces assessments that

reflect health needs and care plans that identify preventative measures for high risk conditions. Typically the social worker is the lead team member responsible for making routine contacts with enrollees; however, for persons with complex health problems, nurses assume that role, enabling them to provide ongoing health monitoring and some direct care. Also, nurses employed by the CMOs are responsible for authorizing the provision of state plan home health services to Family Care members and helping enrollees coordinate their primary health care.

To permit integration of nursing roles into the operation of the CMOs, legislation enacting Family Care exempted CMOs from having to become licensed home health agencies. Without this exemption, they would have been unable to employ nurses on their own staff to provide assessments, case management and routine services such as wound care and medication management and therefore would have to contract with home health agencies for these functions.

**Person-Centered Management Systems and Goals**

Wisconsin's long term care redesign initiative sought to put in place structures that would enable state officials to manage the entire system of long term care, rather than just its discrete parts, in order to achieve person-centered goals. Its approaches to quality measurement and payment methodologies were developed with that philosophy in mind.

**Quality Assurance--**One of Family Care's explicit goals is to improve quality through a focus on person-centered health and social outcomes. Because the program's design was laid out in a comprehensive systems plan, a consistent focus on outcomes could be infused into all aspects of Family Care. Participant goals and values are identified during the individual assessment process, are translated into desired participant outcomes during the service planning process, and form the cornerstone for the state's measurement of CMOs' performance.

During the program's early planning phase, a committee of stakeholders developed a set of 14 Family Care Member Personal Outcomes, listed below.

Family Care Member Personal Outcomes

*Self-Determination and Choice Outcomes*

- People are treated fairly
- People have privacy
- People have personal dignity and respect
- People choose their services
- People choose their daily routine
- People achieve their employment objectives
- People are satisfied with services

*Community Integration Outcomes*

- People choose where and with whom they live
- People participate in the life of the community
- People remain connected to informal support networks

*Health and Safety Outcomes*

- People are free from abuse and neglect
- People have the best possible health
- People are safe
- People experience continuity and security

These outcomes form the basis for four components of the state's quality management system, including the CMO Member Outcomes Assessment Survey, quality indicators tracked by CMOs and reported to the state, CMO performance improvement projects, and state review of a sample of CMO service plans.

The CMO Member Outcomes Assessment Survey is conducted annually with a random sample of program participants. Interviews of participants and case managers are conducted using a process developed by the Council on Quality and Leadership, an accreditation body for long term support programs for persons with disabilities. For each of the 14 outcomes and for each CMO, two survey results are reported: a quality of life indicator, which is the percentage of members who reported that the outcome they desire is present; and a quality of service indicator, which is the percentage of members for whom support for a specific outcome was found to have been provided by the CMO through individual service plans.

Two surveys have been conducted to date, one in 2000 and another in 2001. Since enrollment in Family Care was phased in over those two years, the results of these surveys are considered baseline information and are currently being used to identify areas for quality improvement. The state is making adjustments to the survey as it gains more experience. In particular, focus groups of older persons, family members, providers, and advocates are providing input into the development of a set of outcomes for older people that might be measured differently from the process currently in use.

The member outcomes framework is also the basis for the development of quality indicators that CMOs are required to report on during the contract year. Eleven quality indicators were identified for state monitoring in 2002. For example, an indicator of the outcomes "people choose their services" and "people choose their daily routine" is the percent of members choosing some level of self-directed supports. Each CMO is also required to design and conduct an annual performance improvement project focused on enhancing one of the 14 member outcomes for their enrollees. Finally, the state's quarterly review of a sample of individual service plans examines whether members' service needs, preferences, and desired outcomes are being addressed.

The extensive focus on member outcomes is what makes Wisconsin's quality management system unique. However, it also includes methods that are more traditional and designed to assess operational capacity of both the CMOs and the Resource Centers, such as certification standards, annual site reviews and ongoing reporting requirements.

**Family Care Payments—**Wisconsin makes two types of payments to counties for Family Care. Payments to each Aging and Disability Resource Center are based on state budget estimates of the amounts required to perform the range of functions spelled out in the Resource Center

contract. Amounts paid to each reflect the size of the county's target population and do not vary if the Resource Center serves more or less persons than projected. For fiscal year 2003, total payments to nine counties will be $8.3 million.

Payments to CMOs consolidate the previously separate funding streams of the HCBS waivers, COP, other state general revenue supports, and related Medicaid state plan services into a single capitated amount. By giving one entity the authority to manage all long-term care programs, the state sought to eliminate incentives to shift costs from one program to another and to achieve efficiencies in the use of consolidated resources.

Per member/per month payment rates are based on a combination of factors, including historical costs of all enrolled participants in a county, aggregate functional disability rates of current enrollees as measured by the Long Term Care Screen, a managed care discount and an administrative allowance. Total payments to CMOs in fiscal year 2003 are projected to be $143 million.

Initially, functional measures influenced payment only through the separate rates provided to CMOs for the number of their enrollees at the comprehensive and intermediate levels of care. In 2002, 20 percent of the comprehensive level rate was based on the functional needs of CMOs' members, rising to 50 percent in 2003. Eventually the person-centered functional measure will completely replace rate's historical costs component.

Monthly capitated amounts for 2003 range from the lowest county rate of $1,768 to the highest of $2,368. Variation in payments to counties is expected to decline as the rate's historical costs component is phased out. Monthly payments for enrollees at the intermediate level of care were $641, identical for all counties.

**Coordination of Person-Centered Supports with Community Resources**

Consistent with the value of enabling individuals to live in the most integrated community setting, Family Care has begun a concerted outreach effort targeted to persons residing in nursing homes, community-based residential facilities, residential care apartment complexes, and adult family homes. Resource Centers in the five counties with CMOs are contacting residents of long term care facilities to let them know that staff are available to discuss with them their long term support options, and to inform them of the Family Care benefit and how to apply for it.

At a minimum, Resource Centers must provide this information in a letter sent to each resident of a long term care facility in their counties. An additional method of contact proposed by each Resource Center and approved by the state must be used to reinforce the initial letter. Examples of these outreach methods include meetings with residents individually or in small groups, presentations to resident councils, and telephone follow-up. The statute enacting Family Care requires that these outreach activities be completed within six months after a county begins providing the Family Care benefit as an entitlement.

Residents who want to enroll in Family Care and move to a community setting have access to relocation assistance, which includes help with finding housing and establishing a household.

Funds to cover transitional expenses such as security deposits, utility set up, furniture and other household items are made available to Family Care enrollees, building upon the foundation established by the state's pre-existing community supports programs.

## *Future Directions*

Family Care creates a flexible community supports benefit provided through a care management organization that integrates multiple program authorities into a single delivery system. By all assessments, the program pilots are working well and are on their way to achieving the goals established by Wisconsin's Long Term Care Redesign initiative.

Several evaluations of Family Care are underway. The Lewin Group, under contract with the Wisconsin Legislative Audit Bureau, is conducting a multi-year effort to evaluate implementation of the Family Care pilots and to assess their quality and cost-effectiveness outcomes. Three reports have been produced covering implementation issues, with a fourth due in January 2003 on program outcomes. These evaluations, along with an extraordinary amount of additional information on Family Care, can be found on the Department's web page at www.dhfs.state.wi.us/LTCare. In general, the reports have found that while there are a several issues requiring state attention, the pilots are making good progress toward full implementation and program stabilization.

The Department has contracted with the Innovative Resource Group to conduct the independent assessment of Family Care required by the Centers for Medicare and Medicaid Services as part of its approval of the state's 1915 (b) Medicaid waiver. The external quality review of Family Care required of all managed care programs is being conducted by MetaStar, also under contract with the Department. Since these efforts are just beginning, no findings are available.

The Wisconsin Long Term Care Council, the Department's stakeholder advisory committee charged with overseeing implementation of Family Care, issued in November 2002 a resounding endorsement of the program's experience so far and called for short term steps to achieve a long range goal of statewide availability by 2010. Specifically in the short term, it recommends expansion of the program to additional counties to reach the level authorized by the Family Care statute, which is coverage of 29 percent of the state's eligible population. In 2001, the legislature appropriated funds to establish a Care Management Organization and Family Care benefit in Kenosha County, which had already been operating an Aging and Disability Resource Center, as well as start up funds for additional counties. Both measures were vetoed by the Governor. Achieving program expansion will be a top priority for advocacy groups during the 2003 legislative session.

Measures of the program's cost effectiveness are currently being developed. The Lewin Group will be addressing this issue in its next report, and the Department is also looking at ways to assess whether the savings it has been able to achieve on a per capita basis are sufficient to cover the additional numbers of persons served by Family Care through its entitlement. On a per capita basis, the state calculated that for calendar year 2001, it spent on average 9.6 percent less per Family Care enrollee than it would have cost to serve a similar population in a fee for service environment.

Finally, as the state looks to renewal of its 1915 (b) waiver, it needs to develop a strategy for competitive procurement of CMOs. The Centers for Medicare and Medicaid Services allowed Wisconsin to designate counties and tribes as the sole eligible entities during the program's initial start-up phase, but in the future, competitive procurement based on quality and capacity will be required.

## *Lessons Learned*

Wisconsin's long term care redesign effort had some relatively simple sounding goals, such as provide people with better choices, improve service access, improve quality through a focus on outcomes, and create a cost-effective system. Achieving reforms, however, was hardly a simple task. The complexity of Wisconsin's well-developed array of community supports programs meant that on the one hand, state officials had an extraordinary amount of experience in designing service innovations. On the other hand, these successes contributed to an increasingly fragmented service delivery system.

Wisconsin's experiences can yield valuable lessons for other states as they undertake major systems reform. Four critical elements contributed to the state's success: state level capacity, local level capacity, approach to program design and the systems reform process itself.

***State level capacity***—Visionary state officials, extremely capable program managers and a depth of staff expertise in the state offices that led the systems redesign effort were crucial elements of Wisconsin's success. Their experience in designing and implementing other complex community supports systems and the climate of innovation they fostered enabled them to develop both the design for change and the program tools and structures necessary for making the design a reality.

Creation of the Center for Delivery Systems Development was a critical factor to the state's success in establishing the new Family Care Program. Since Medicaid state plan services and Medicaid home and community based services are managed in different parts of the department, coordinating state policy on long term care can be difficult. Through its placement in the Office of Strategic Finance, the Secretary's budget office, the Center for Delivery Systems Development was able to link institutional and community based program policies in designing integrated service delivery under Family Care.

***Local level capacity***—In Wisconsin county governments have developed extensive expertise in administering the state's home and community-based supports programs. This experience, coupled with a level of public accountability that private organizations cannot achieve, made them a natural choice for managing Family Care.

What they lacked, however, was experience in managing the complex financial aspects of a risk-based managed care operation. Although state officials offered counties the assistance of a financial consultant to help them design their fiscal management systems, none of the counties initially availed themselves of this resource. As they came to appreciate the need for business-oriented experience, they have accessed this resource. At this point, the counties have by and large developed the necessary capacity, but state officials have observed that when the program

moves into additional counties, it will be important to address financial management capacities from the start.

***Program design***—At the outset, Wisconsin developed a comprehensive plan for systems redesign, which proved to be an essential step in ensuring that the guiding principles and goals were consistently reflected in all aspects of Family Care. Having a well mapped out strategy also meant that the state was better able to achieve its goal of managing the whole system rather than its component parts. As illustrated in the discussion of Wisconsin's approach to quality, a focus on participant outcomes was truly built into all aspects of Family Care.

***Systems reform process***—Wisconsin's long term care systems redesign effort began with the achievement of a broad based consensus among key stakeholders on the values, principles and goals that a new system of community supports should reflect. The benefit of this approach, as described in detail earlier in this report, is that all stakeholders have a common understanding of what the new system is expected to accomplish for participants. Furthermore, as both program design and implementation proceed, a strong values framework provides a guidepost for decision making on a wide range of issues and for resolving conflicts about competing strategies.

Wisconsin's systems redesign effort was truly a partnership between state officials and stakeholders. As a result, all have a shared investment in bringing their plans to fruition. Strong stakeholder involvement continues through participation on the numerous advisory and governing bodies created to oversee Family Care implementation. Having widely shared values has fostered a mutually supportive collaboration among state officials, counties and stakeholders that so far has kept them all focused on achieving the goals of long term reform.

## *Bibliography*


Wisconsin Department of Health and Family Services:

"Redesigning Wisconsin's Long Term Care System: Proposal of the Department of Health and Family Services", July 31, 1998.

"Summary of the Questions and Answers from Consumer Forums on Long Term Care Redesign", 1998.

1915(b) and 1915(c) Medicaid Waiver Applications

Bureau of Aging and Long Term Care, Department of Health and Family Services, "Contract for Enrollment Consultation Services".

Office of Strategic Planning, Center for Delivery Systems Development, Department of Health and Family Services:

"Being A Full Partner in Family Care"

"CMO Member Outcomes: The Baseline Assessment', March 2001

"CMO Member Outcomes: The 2001 Assessment", April 2002

"History of LTC Design"

"Family Care Progress Update", May 2002

"Family Care Update", quarterly newsletters

Memos to Resource Centers and Care Management Organizations

"Quarterly Family Care Activity Report", September 2002

"Resource Center/CMO Quarterly Narrative Report Summaries"

"Testing the Reliability and Validity of the Wisconsin Long Term Care Functional Screen"

"Wisconsin Family Care Resource Allocation Method"

2002 Health and Community Supports Contract

2002 Resource Center Contract

The Lewin Group: Lisa Maria B. Alecxih, Karen Linkins, Sharon Zeruld, Christina Neill. "Wisconsin Family Care Implementation Process Evaluation Report II", August 13, 2001

The Lewin Group: Lisa Marian B. Alecxih, Steven Lutzky, Karen Linkins, Sharon Zeruld. Christina Neill. "Wisconsin Family Care Implementation Process Evaluation Report", November 1, 2000.

Menga, Richard. "Community-Based Long Term Care Programs Informational Paper", Wisconsin Legislative Fiscal Bureau, January, 2001.

Wisconsin Council on Long Term Care:

"Annual Report of the Wisconsin Council on Long Term Care", May 2001

"Future Policy and Funding Directions for Long Term Care in Wisconsin, Recommendations of the Wisconsin Council on Long Term Care", November 20, 2002

Monthly Minutes